



Preferences of People 50 Years and Older when Thinking of their Future Care Needs

RESEARCH

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ABSTRACT

Context: The growth in the older population and its diversity will impact the overall demand for social care and potentially affect patterns of preferences. Different initiatives have been implemented in England to improve care provision to make it more personalised, better informed and interconnected.

Objective: To understand preferences for different aspects of models of social care for older people and to explore how those preferences might change in the future if their care needs increase.

Methods: We conducted five focus groups (1.5 hours each) with people aged 50 years and older. Participants were selected using purposive sampling to capture the heterogeneity of the English population. We categorised comments during the focus groups into five themes (housing settings, community assets, use of technology, provision of care, control and dignity). The unit of analysis was the individual.

Findings: People value their independence and control over their lives; they prefer models of care that allow them to have their own space for as long as possible. They emphasise the importance of community assets and attach high priority to maintaining social connections with their neighbours and having access to local facilities. Building a relationship with their care provider was essential to receiving good quality care. We found differences in preferences for some components of care between participants from different ethnic and socioeconomic groups.

Limitations: The focus group discussions might have introduced social desirability bias. The design might limit representativeness of the sample. We included people from different ethnic and socioeconomic groups, but we could not include people from the widest range of religions or sexual orientations.

Implications: Our study yielded rich insights into how people value different components of care, with differences between socioeconomic and ethnic groups that highlight the need to ensure that care packages align with people's individual preferences, beliefs and values. However, there is a noticeable lack of knowledge about the care options that people could access when planning for their future if their care needs increase.

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CONTEXT

The world population is ageing, presenting several challenges for individuals, families and communities related to changes in physical and mental functioning (Nguyen et al., 2020). Projections of the English population estimate that the number of people aged 65 and over will increase by 41% between 2018 and 2038, from 10.1 to 14.3 million, and of those aged 85 and over by 72%, from 1.4 million in 2018 to 2.3 million in 2038 (Hu et al., 2020). Importantly, the English population is becoming increasingly diverse, with a growing number of people from different ethnic groups and a mix of religions, languages and identities (Office for National Statistics, 2022). The number of older people unable to perform at least one basic activity of daily living (ADL) is projected to rise by 48%, from 3.5 million in 2018 to 5.2 million in 2038 (Hu et al., 2020), and the number of older people with four or more long-term conditions is projected to more than double between 2015 and 2035 (Kingston et al., 2018). This growth in the older population, particularly of older adults living with long-term conditions, and the increasing diversity will both impact the overall demand for social care and potentially affect patterns of preferences (Kingston et al., 2018).

Policymakers acknowledge the need for a person-centred model of care and not a “one-size-fits-all” approach, where care is provided in a holistic and integrated way, centred around valuing and involving older people, their carers and family members in decision-making to ensure people are able to express and hopefully achieve their preferences (Bennett et al., 2018). This person-centred model of care is based on the preference-based model of care, which, building on other theories and models, provides a theoretical framework to explain how individual preferences, as expressions of needs, values and goals, direct behaviour to meet needs and thus positively affect wellbeing (Van Haitsma et al., 2020). Moreover, preferences will be influenced by past experiences and the context in which the individual has lived. Thus, there is a need to understand individual and cultural differences in the relative importance of preferences in the English context.

Evidence on new models of care emphasises the importance of a preference-based model of care when planning and providing services for individuals to tackle issues around loneliness and isolation, build strong relationships, support independent living in one’s own community whenever possible (Robinson et al., 2020; Abramsson & Andersson, 2016) and help older people maintain their dignity and autonomy (Hill et al., 2017). There has been increasing advocacy for more community-based approaches to care provision (Bennett et al., 2018), suggesting greater roles for communities in recognising links and connections for support and provision of care, both formal and informal. The COVID-19 pandemic has

highlighted the need for care provision to be part of a much broader local offer in each community (Locality, 2021). Community-led care is often able to provide more personalised options, giving individuals greater choice and control in decisions regarding their care (Locality, 2021; Buurtzorg, 2006; Battersby, 2015; The King’s Fund, 2012; Bennett et al., 2018).

Many different initiatives have been implemented in England to improve care provision to make it more person-centred, better informed and interconnected. When implemented well, these models of care can improve the satisfaction of people who use social care, giving individuals more choice and control over their decisions and lives (King, 2021b; King, 2021a). They can also have positive impacts on workforce stability, providing better opportunities to build strong and meaningful relationships between individuals and their carers (King, 2021b). In this study, we aimed to understand current preferences for different aspects or characteristics of models of social care for older people and to explore how those preferences might change in the future if their care needs increased. We focused on examining what people in England consider important when thinking about their future care to inform policymakers on key components that new models of care should incorporate for long-term planning.

METHODS

We conducted an initial scoping search of published literature on preferences for care to identify characteristics or components considered to be most relevant for people when thinking about their care choices and in shaping the quality of life of older people with high care needs. These components went through an iterative consultation process with an advisory group and policy officials from the Department of Health and Social Care (DHSC). We constructed a topic guide for discussion in a series of focus groups.

We conducted five focus groups of seven or eight participants each between March and June 2022, each lasting 1.5 hours, with people aged 50 years and older because we wanted to look at the preferences of people when thinking about their own current or future needs. Participants were selected through an external organisation, the Caribbean and African Health Network along with the Greater Manchester Older People’s Network Health and Social Care Working Group, to ensure we had a diverse group of people. Participants were selected using purposive sampling to capture the heterogeneity of the English population by reference to age, ethnicity, socioeconomic status, and place of residence. First, the recruitment process for the first three focus groups focused on adult participants from different age groups, genders and places of residence, without

specific quotas for ethnicity or socioeconomic group. Subsequently, the second recruitment process for the two further focus groups focused on adult participants from (a) different ethnic groups from members of the Black Afro-Caribbean community and (b) with people from lower socioeconomic groups (defined by income using the UK Office for National Statistics social grade categories) using the external company's existing panel of members of the general public (who often tend to be underrepresented in these kinds of consultation processes). The participants did not themselves have high care needs. They were asked to think about the future.

The focus groups were semi-structured discussions of the preferences of participants between the selected types and components of care. Two focus groups were face-to-face and three were virtual using Zoom. Written or oral informed consent was obtained from participants before the focus groups. All focus groups were audio-recorded with permission, and recordings were transcribed verbatim.

The qualitative data was analysed using thematic analysis (Vaismoradi et al., 2013). We categorised the data into five different themes linked to the components of care selected for inclusion, with the unit of analysis being the individual. The first theme looked at housing settings and had four sub-themes: preferred housing-with-care setting; people to share the home with; ages of co-residents; and geographical location. For the purposes of this study, we categorised the various housing-with-care settings into two overarching groups: home care and residential care. Home care includes all settings where the person can live independently in an owner-occupied or rented home with their own front door. This group can be further categorised into mainstream home, living with family and community settings. Community housing settings include various forms of 'specialised' homes to buy, rent or access through private or social and affordable rent schemes built within a development to support independent living with appropriate levels of care and support depending on preferences and needs (Robinson et al., 2020). Residential care settings comprise those where the person does not live independently with their own front door; they include places where personal care and accommodation are provided and regulated together as one package and are communal establishments rather than independent living (Social Care Institute for Excellence, 2021). These settings include nursing homes and residential care homes (Stirling & Burgess, 2021).

The second theme explored the resources provided by the community that were considered most important for participants' wellbeing and care, and the third theme looked at the use of assistive technology for care. Assistive technology in the context of care refers to 'any device or system that allows individuals to perform tasks they

would otherwise be unable to do or increase the ease and safety with which tasks can be performed' (Lariviere et al., 2021). There is a broad range of different assistive technology tools that aim to support people to maintain or improve their personal control and independence and to continue living at home for as long as possible. Assistive technology can help reduce potential risks, as well as support the work of paid or unpaid carers and enable care through tools for remote alert and monitoring (Damant et al., 2017).

The fourth theme explored the provision of care, with two sub-themes: provider of care and use of direct payments. In England, direct payments are cash payments for care that can be chosen instead of a care package arranged by the local authority. Finally, the fifth theme focused on control and dignity, with three sub-themes: decisions on daily routine and flexibility of care provision, management of money, and spiritual, cultural, religious, and sexual identity.

Analyses were conducted in NVivo 16.1. Ethical approval was obtained through the London School of Economics and Political Science research ethics process.

FINDINGS

In total, there were 39 participants in the focus groups: 10 males and 29 females. Mean age was 67 years, ranging from 50 to 85. Twenty-six were white British, 12 were Black Afro-Caribbean and one was Indian. Participants came from different socioeconomic groups: C1 (supervisory, clerical, and junior managerial, administrative and professional occupations), C2 (skilled manual occupations), and DE (semi-skilled and unskilled manual occupations; unemployed and lowest grade occupations). Places of residence were the North West, Yorkshire, the East Midlands, London, and South East England. The overall composition of the five focus groups reflects the general diversity of the English population, although a sample as small as this cannot be fully representative. Due to the way information was collected, the information provided by each participant reflects whether they were in the first or second focus group. Thus, some provide age, gender, ethnicity and socioeconomic status, whereas others provide only information related to age, gender and ethnicity.

THEME 1: HOUSING

Housing with care settings

The discussions held with participants of our focus groups about housing with care showed that, in general, individuals preferred to stay living independently in their own homes for as long as possible. This preference was especially stressed by participants from higher socioeconomic groups, who usually described wanting to live independently in a well-suited home. All participants

would consider making physical adaptations to their homes, such as shower rails, if needed. Community settings were also positively accepted as a housing option if care needs increased.

Yeah, I totally agree. I would live at home for as long as possible. I have a three-bedroom semi at the moment, but I have considered selling up and trying to find a two-bedroom ground floor apartment. (Female 77, White British, SEG C1)

Participants considered moving to a community setting as an opportunity to receive good quality care while maintaining their independence if these settings provided their 'own front door'. This was especially highlighted by participants from lower socioeconomic groups (D and E), who mentioned that they would prefer to move to a community housing setting as the first option rather than stay living in their current homes. However, there was discussion about the costs associated with moving to community settings and how they felt that it would limit their choice.

I'd prefer a community where I'd have my own place, but yet would have like a communal front room where we could all go and meet if we needed. But you have still got my own like little flat really. That's what I would prefer. (Female 58, White British, SEG D)

...but I'd prefer the community. But I've been looking into it and they just price you out of it. For what I'm paying now for my own home, it's like that plus another half to rent a room. It is expensive. (Male 62, White British, SEG E)

Residential and nursing care homes were the least preferred housing settings. These settings were seen as outdated, and participants frequently mentioned the poor quality of care that they thought people received when living in care homes.

The discussion with participants from Black Afro-Caribbean groups showed the interaction between their culture and the options of care available, something that was not mentioned by other participants. In general, their preference was driven not only by the value they placed on their independence, as with other participants, but also by their cultural background, which they described as encouraging a more intimate relationship between families and their own communities, with more engrained interactions. They mentioned that, when people age, it is assumed that their children or family members will take care of them, so parents usually move to their children's homes (or vice versa). Also, they explained that their culture encourages forming strong and close social connections with a strong sense of community, and they

agreed that they usually support and provide unpaid care to people within their close communities. However, when discussed further, participants discussed the difficulties of caring for a family member and the worry of becoming a burden for their children.

...coming from my culture back home is that we don't have people in [care] homes. The family looks after them. So, I have got five children and I'm hoping when I get old that they would look after me either in their homes or come to my home and look after me because I do believe that when a person gets old after looking after so many children that they should be put in homes. It the children's responsibility and the grandchildren to look after the elderly. (Female 74, Black Afro-Caribbean)

Yes. There is way to – it's very fundamental that people stick together. When you're old, the children, the grandchildren take care of you until you die. That's the way, from my background in Africa and then most of Caribbean that is the same way we go, I used to visit a lot of them in the Caribbean. (Male 55, Black Afro-Caribbean)

People to share their home with

This sub-theme focused on exploring the preferences of individuals regarding who to live with in circumstances where they cannot live independently because of their increasing needs for help with daily living and personal care tasks. We discussed if participants from the focus groups would prefer to share their home with a relative, if they would consider letting a room under a home-share arrangement, if they would prefer to receive care from a live-in carer in their own home or if they would consider moving to a carer's home as in a Shared Lives arrangement ([Shared lives plus, 2022](#)). Preferences were mixed regarding sharing their home if they were not able to live independently, with some participants mentioning how difficult that decision would be and that they had not thought about it before. Some participants would prefer to live with a family member, although it was agreed that feeling a burden would hinder this choice. There was a strong preference for maintaining their independence and privacy, even if that meant living on their own and receiving care from a person who comes every day to support them with their daily activities. When discussed further, some participants agreed that they would prefer to live with a formal carer in their own homes, mentioning that this arrangement would make them feel safer, especially during the night.

It's an awful thing to think that you've got to depend on somebody, I think, and if we do have to do it then, as I said, nobody knows what's around

the corner, do they? I suppose I would prefer them to come here, to do their things and then go back home. (Female 71, White British, SEG D)

There was a negative perception towards a home-share arrangement, and participants highlighted that they would not feel comfortable living under this arrangement, again giving importance to feeling safe at home.

Because I think you're better with friends and neighbours and family who you're used to, rather than strangers. (Female 77, White British, SEG C1)

Ages of co-residents

The next sub-theme focused on discussing the preferences of individuals about the age of their co-residents if living in a community housing setting. In general, participants from the focus groups agreed that they would prefer to live with people of mixed ages with a minimum accepted age, as they considered that it was important to be able to talk about different topics and socialise with people of different ages. However, they would not like to live somewhere that was too noisy. They specifically mentioned loud music and parties.

I don't think they should mix the young with the old. We're set in our ways, unfortunately, and it's like you just want a bit of peace like later on, don't you? (Female 61, White British, SEG D)

Mixed ages for me too... I think you don't want to be with all old people, because a lot aren't young at heart, are they? ... and I think if you're mixing with younger people, it keeps you feeling younger. (Female 74, White British, SEG C2)

When we asked them for a specific age limit, participants agreed that around 50 years old would be an appropriate age limit for this type of community housing setting.

I'd be happy – I mean, obviously, somewhere around about my age group. There's no point talking to someone in their 30s about rap music, because it'd be like, "Well, what are you talking about?" But anything sort of my age group that you can talk about stuff from the 70s, the 80s and all by that time, because we'd be all old fogies and anybody else that's younger than us wouldn't really understand. So yeah, something like that, something our age. I don't know – you could set an age limit to it. I don't know – 50+ or 55+ I don't know. Starting from there. Something like that. (Male 55, White British, SEG C2)

Geographical location

Participants would prefer to continue living in their current neighbourhood, this being the main driver for choosing

where to live when they age or as their care needs increase. We discussed the benefits of living in a familiar place, where they know all the resources available and the social connections they have with neighbours and families. When we discussed moving to a housing setting in the countryside or other geographical locations, they all agreed that, although it would seem nice, they would not move away from their families or communities.

Just my neighbourhood because you know people there, you're handy for your relatives. You can't move away and then expect your relatives to travel and visit you. So, I'd stay in the same area. (Male 75, White British)

I think I'd prefer to stay in my own home with my friends and my family. My family and grandkids live about 10 minutes' drive away. It's where all your memories are and where I think you'd be most comfortable. (Male 76, White British)

THEME 2: COMMUNITY ASSETS

This theme focused on exploring the preferences of older people about which resources provided by the community were considered most important for their wellbeing and their care. We discussed the importance of having access to informal services and support provided by the community and linking to and maintaining the social connections provided by and within the community. All participants considered the links they had with their respective communities and neighbourhoods as important, especially during the COVID-19 pandemic. They also agreed that new models of care should promote community-based care and value community life and social gathering as necessary for their wellbeing. They mentioned that key assets were the availability of good public transport, local shops, a library, pubs and community centres so they could engage in different activities.

Within the community, because these places are just going to – they're dying out, so to have something like that would be nice. A little pub, pop-up pub or something like that. (Female 58, White British, SEG D)

Almost all participants mentioned the importance of having good public transport, mentioning some free services that allowed them to move around their community easily, which they previously used but were no longer provided.

And they'll pick you up and take you to wherever. So, I think that's good to keep in a community, because at least you've got the access. And the drivers are like, become their friends... And that's part of the community, and that's taking them to

bingo or wherever they want to go. That's a good setting. (Female 61, White British, SEG D)

The Black Afro-Caribbean group mentioned the importance of having good access to Afro-Caribbean food shops and accessibility to participate in Sunday church services.

I think the important thing that has been mentioned is access. Access to these areas so the transport is a very important element of that, being able to get there affordably. So, it doesn't necessarily just mean African Caribbean shops, but it means a range of shops, the accessibility is key. (Male 63, Black Afro-Caribbean)

THEME 3: USE OF ASSISTIVE TECHNOLOGY

All participants in the focus groups acknowledged the use of technology as important and beneficial in maintaining their independence for longer and helping them with their daily activities as their care needs increase.

I think technology has a role to play, because I have seen where it has really helped. (Female 81, Black Afro-Caribbean)

However, all participants recognised the existence of the 'technological divide' and that the lack of digital skills was a barrier to fully engaging with it. They highlighted the importance of receiving appropriate training so they could first understand the usefulness of digital and other devices and then be able to make a more informed decision about whether or not they would use them.

I would like to see certain aspects of what could be introduced to help me stay at home and learn about it, what would the benefits be, and as I move forward to increase it to other things. But you need to teach me. (Female 74, White British)

Also, they mentioned that, in order to be able to fully uptake the use of assistive technology devices and feel comfortable using them, they would need to receive ongoing support because of the rapid and continuing changes in technology that sometimes made them feel overwhelmed or that they would not be able to keep up with the updates.

And it's a shame for the older people, because they're not catching up as quick. (Male 62, White British, SEG E)

When we discussed the types of devices, participants agreed that they would feel comfortable with assistive devices such as smartwatches, pressure mats or monitors that took their physiological measures, as

these technologies would help them feel safer at home. However, there were differences in preferences about the use of cameras in their homes. Some participants said they would consider having cameras to monitor their activities and help them feel safer, while others were against it because of the lack of privacy and feeling that they were being observed.

Yeah, I'd be quite happy with the camera, if someone is checking up on you every so often. I think that's quite a good idea, or even a tracker on you or something. (Female 50, White British, SEG D)

That's very invasive, isn't it, intruding on our lives. I mean, I can hardly understand the present IT system we have, never mind all these complicated devices that they're going to bring out. But also, I would prefer that Big Brother isn't watching me. (Female 74, White British)

THEME 4: PROVISION OF CARE

Provider of care

Among the participants in the focus groups, the majority had experienced either providing or receiving unpaid care by a family member or a friend. They acknowledged the burden involved in caring and mentioned that their preference would be to receive care from a formal care worker as their main provider of care.

I think it depends on the family's situation because if the family is working they can't give 24 hour care, so it could be a combination with help from outside to help them...I don't think it's fair to put the complete burden on the family because they have their lives also. (Female 56, Black Afro-Caribbean)

When we discussed if they would prefer receiving care from the same or varying carers, all participants agreed that they would prefer to receive care from the same person and not from different staff on different days, as they considered this essential to building a relationship and confidence.

I would prefer to have carers that come in and I know, rather than a bunch of people that just keep rotating all the time. Because obviously, they'll get to know you, you have a rapport with them...they know what your needs are, they know what your habits are, the routines... (Male 55, White British SEG C2)

And he has care, but he gets a different carer every other day. It's not often that the same carer comes and he's fed up to the back teeth of it. He

has to explain what to do, and now he's got the point where he won't do anything. He'll just lie in bed... (Male 66, White British SEG C2)

Also mentioned was the importance of building a relationship, which is essential to receiving good-quality care as it enables the carer to know the preferences and needs of the person. This made it possible to more easily perceive when something unusual or wrong was happening and needed attention.

And you build up a relationship – I know that sounds like a strong word, but you build a relationship up, and then you would hopefully think that that carer would say, “Are you alright today? You seem out of sorts.” (Male 54, White British SEG D)

As part of the discussion, participants highlighted the importance of the experience of the carer and emphasised that receiving high-quality care was one of the most important aspects when making decisions and choosing their care provider.

“Yeah, I think all of those things that she said, but personally, I couldn't care less who it was, providing they are well-trained.” (Female 73, White British)

Use of direct payments

The groups also focused on discussing their preferences regarding direct payments, but only a few participants had experience with this approach. In general, older people in the groups were better informed than younger participants and understood the scheme, but there was a general lack of knowledge of the existence of and access to this scheme. People did not know who could access this scheme and what they could use it for. After we explained what direct payments were, participants discussed that it would be a useful component of their care but that they needed more information about it. They agreed that, if using this scheme, they would prefer to manage it through an agency. This would make them feel safer, and they would be able to hold the agency accountable for the spending.

I think I would go maybe down the agency side, mainly because, just employing someone, if you could check them out and police checks and all that, I think probably – just personally – using an agency would be most likely safer. (Female 77, White British, SEG C1)

THEME 5: CONTROL AND DIGNITY

Decisions on daily routine and flexibility of care provision

Focus group participants mentioned the importance of being able to decide what to do in their daily lives

to maintain their independence, control and dignity as individuals. They considered it important to have routines, valuing models of care where they could have flexibility in decisions about their daily routines and their care. Participants in focus groups stressed the importance of being able to choose their meals and the type of food they wanted to eat, as well as how important it was for them to be able to go to the shops and choose their own food.

...sit down and discuss a package and say, “Right, well I want a meal in the morning, a meal at dinner,” or, “I want somebody to come in first thing in the morning, last thing at night.” To be able to choose. (Female 50, White British SEG D)

Yeah, I think you need to have a lot of control over what time you want to get up, what time you want to go to bed, what time you want to do everything. You don't want someone coming in and going, “Right, here we go. There's a routine. This is what you're doing for the next week. This is what time you're getting up, breakfast, whatever.” You've got to have some kind of structure to your day, but whatever you want to do, not what someone else wants to tell you. And they'll fit it around because we can't do it until the carer has come in. (Male 67, White British SEG C2)

Management of money

Another aspect of maintaining control and being treated with dignity is the ability of the person to manage their own money. We discussed with participants if they would prefer to manage their money for as long as possible or if they would prefer someone else to do it. Since the ability to manage their finances may not be in the person's control, for example, if they develop severe dementia, we framed it to reflect the value of maintaining control over their own life. They all agreed that it was an important aspect of their lives, and they would prefer to manage their own finances for as long as possible and would consider power of attorney for a trusted family member when they would not manage them.

Spiritual, cultural, religious and sexual identity

The more intimate interaction between family members that we discussed with participants in the Black Afro-Caribbean group demonstrates the importance of considering cultural backgrounds when planning and providing care. Participants from this group also mentioned the importance of flexibility in their care and good accessibility to community life, as well as their religious ceremonies and celebrations, as a way of respecting their cultural and religious beliefs.

That's what we're missing here. That's what friends all over the country are saying, that is what is missing. So, we're looking at a model for older people, when it comes to social care, is to find a fit. And also, ensure that companies that are trying to fit an ethnic background that the government and local authorities help them to realise the standards that they need to meet. (Female 85, Black Afro-Caribbean)

There were also differences between groups in the importance they attached to food and hygiene, with people from the Black Afro-Caribbean group highlighting that these aspects can often be overlooked by carers of other cultures and therefore become unmet needs.

The meal is not catered to Afro Caribbeans, to ethnicities, it was at the beginning but whatever happened with their funding that's gone. So, now they have meals that she doesn't eat so that's a waste of money she has to pay for. (Female 74, Black Afro-Caribbean)

I don't say that the English don't cook properly but they too, the Black want their home and it has seasoning, and taste, and that will help them. (Female 85, Black Afro-Caribbean)

So, how you wash an elderly Black woman or elderly Black man, you would say everybody washes the same. Nowadays in care homes with these wipes, people use wipes to wash their face, do your arms, do your breaks. That is not a wash for a Black woman, is it? It's not a wash for a Black woman. Well, for a Black person. We wash with water and soap. And so, these may be small things, but they are crucial to our preference. (Female 74, Black Afro-Caribbean)

DISCUSSION

Our study shows that, when thinking about needing care or support in old age, people value their independence and control over their lives, which then translates into a preference for models of care that allow them to stay in their own home or move to a community housing setting with their own space for as long as possible. Our findings align with the Preference-Based Model of Care, which suggests how the expression of individual preferences shapes behaviour and how these preferences are shaped by individual and cultural differences within a particular social, cultural and political context (Van Haitsma et al., 2020). However, the findings showed that participants had limited information on the different options of care they could access when their care needs increased or where

to find information. People from lower socioeconomic groups indicated that their preferences for a community housing setting would also be an opportunity to receive good-quality care while maintaining their independence. However, they expressed concerns regarding the costs of these different community housing options, which would directly limit their choices. It is also important to consider the influence of cultural background when choosing where to live, as shown by the value that people of Black Afro-Caribbean descent place on their culture, where there is an intimate relationship between families and their communities.

The views expressed by participants in our focus groups emphasised the importance of community assets when people plan their care, such as good public transport, shops and community centres. They also mentioned how the relationship with neighbours developed positively during the COVID-19 pandemic, enhancing the importance they give to community life. Relationships with neighbours, access to local facilities, and proximity to good transport links were key factors encouraging people to want to remain in their own home. These findings were closely related to participants' preference to stay in their own neighbourhoods. Several studies have similarly shown the strong attachment people have to their communities, enabling them to establish trust, a sense of belonging and the ability to rely on their neighbours (Lloyd & Parry, 2015). This has been further reinforced by the COVID-19 pandemic. Therefore, an important priority for new models of care is to promote or maintain social connections between older people and their neighbours, support participation in community life and ensure access to local facilities (Bennett et al., 2018, *Associated Retirement Community Operators and Later Life Ambitions*, 2020).

The use of technology has surged rapidly in recent years, with the COVID-19 pandemic increasing its use considerably. There is some evidence showing that, when used, technology has facilitated older people to stay safe while isolating, receive care and maintain their social connections (Chang et al., 2021; Jutai & Tuazon, 2022). It has also facilitated older people's care, improving their psychological well-being, reducing anxiety and helping people feel optimistic about the future (Damant et al., 2017; Beech & Porteus, 2021). Participants from our focus groups acknowledged the value of assistive technology devices to support their care and maintain their independence, but they highlighted the cost barriers and technological divide that limit their use, especially in older people or when younger participants think of their use in the future. That 'divide' has been highlighted in several studies (Spann et al., 2022; Office for National Statistics, 2021; Beech & Porteus, 2021), highlighting the importance of providing constant support for a more widespread use and to support individuals with their needs (Lorenz et al., 2019).

As discussed in the focus groups, building a relationship with a care provider based on trust and confidence was seen as essential to receiving good-quality care. Participants described this relationship as needed to enable the carer to know their preferences and needs and thus provide better tailored support and make them feel safer (Kruger, 2021). Similar to our findings, studies have shown that people consider being treated with respect and dignity and being involved in decision-making as highly important characteristics that they would look for when choosing their care provider (Cleland et al., 2021). This highlights the need for independence, autonomy, choice, control and privacy as ways of promoting their dignity (Hall et al., 2014; Hall et al., 2009). Also, our findings emphasise the value people place on having daily routines and wanting to be involved in decisions affecting them, such as the activities they do, the visits they receive, the time they get up and go to bed, the food they eat and the timing of meals. Evidence on the preferences of people living with dementia (Wehrmann et al., 2021; de Boer et al., 2007) shows the importance of considering autonomy, sense of control, decision-making, feeling that one still has a purpose in life and a wish to engage in meaningful activities without being stigmatised in their care (Milte et al., 2016). Similarly, studies focusing on people receiving end-of-life care show that this group of individuals attaches importance to maintaining independence and autonomy, feeling safe and being treated with respect and dignity (Denning et al., 2013; Hill et al., 2017).

Our findings on the preference for receiving care that respects spiritual, cultural, religious and sexual identities align with the findings of other studies, emphasising the weight that people place on this component of care (Cleland et al., 2021). This includes receiving care from trained and skilled staff who understand and are able to provide care that responds to the different or specific needs of individuals from diverse cultural and ethnic backgrounds or with diverse religious beliefs and sexual identities (Ward et al., 2010; Selman et al., 2018). It is essential for care providers to be well trained to manage the impact of discrimination, stigma and misgendering associated with gender and sexual identity, which can exacerbate mental and physical health problems (Age UK, 2021). As mentioned previously, the more intimate interaction between family members that we discussed with participants in the Black Afro-Caribbean group is another example of the importance of considering cultural backgrounds when planning and providing care. Previous evidence has shown the importance of this interaction, where there is more family-based decision-making around care arrangements that can sometimes go against the person-centred model of care that seeks to maintain the autonomy of the individual (De Souza et al., 2020).

STRENGTHS AND LIMITATIONS

Our study has several limitations. The design of the study, relying on focus groups and qualitative analyses, might limit the representativeness of the sample. We used purposive sampling to try to ensure inclusion of participants, differing by age, gender, ethnicity, socioeconomic status and region of residence, to try to capture the heterogeneity of the English population. The selection of the focus groups was done through an external organisation, the Caribbean and African Health Network and the Greater Manchester Older People's Network Health and Social Care Working Group, to ensure we had a diverse group of people. Our study yielded rich insights into how people value different components of care, with differences between socioeconomic and ethnic groups. However, we could not include people from the widest range of religions or sexual orientations, and that would need to be considered in further research.

There are also challenges related to the use of focus groups and the engagement of participants in the discussion. Focus groups were chosen for their convenience in enabling participants to share a broad range of views regarding their preferences of care and provided the opportunity to discuss further some topics when further clarification was needed, such as in the case of direct payments. However, the quality of the discussion was highly reliant on the facilitation and moderation of the focus group, making it more difficult to control and manage, especially when having participants with stronger voices and opinions. Also, they may introduce social desirability bias in the responses of participants, where participants may conform to the dominant opinions within the group. To overcome some of these limitations, we conducted focus groups with a small number of participants each, so that everyone could participate in the discussions. Also, at the beginning of each focus group, we assured the group that there were no right or wrong answers. We reminded everyone that they could participate in the discussion, and throughout the focus groups, we invited everyone to share their thoughts.

CONCLUSIONS AND POLICY IMPLICATIONS

Our study provides new evidence on the views of older people in the period after the early waves of the COVID-19 pandemic about the care of older people with high care needs. We are not aware of other evidence relating to the views of older people on this topic expressed after the height of the pandemic, which may have changed people's views about care. This study is part of a wider project designed to inform a survey of people aged 50 and over to understand their views and preferences relating to the care of older people with high care needs.

People value independence and control over their lives. Consequently, they prefer care options that allow them to stay in their own home or move to a community housing setting with their own space for as long as possible. They emphasise the importance of community assets when planning their care and attach high priority to maintaining social connections with their neighbours, valuing community life and having access to local facilities. Participants in our study considered that building a relationship with their care provider based on trust was essential to receiving good-quality care. We found differences in preferences for some components of care between participants from different ethnic and socioeconomic groups; these highlight the need to ensure that care packages align with people's individual preferences, beliefs and values. Previous studies and our focus group discussions also touched on concerns regarding the costs of care. There are clearly affordability barriers that limit some people's access to what might be their preferred model or quality of care that are pertinent when considering future care policies.

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COMPETING INTERESTS


The authors have no competing interests to declare.

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